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LETTER FROM THE CHIEF EXECUTIVE

Dear Friends

As we come to the end of a wonderful year, we are so privileged to have been part of the worldwide children's hospice and palliative care movement. The voice of the child with a life-limiting or life-threatening condition has been heard and respected, through the activities of so many "champions" around the world, and the work of the ICPCN and other organisations such as the European Association of Palliative Care Children's Steering Group, with a similar vision for a world where children receive the palliative care they need and deserve.

While collecting the beautiful children's stories in our publication "Touching Rainbows" we realised the importance of providing a gentle space for children and their families to share their experiences and their journeys; and to have their personal stories heard.

This past week I have been watching the development of Radio Diaries by children in Bloemfontein. Led with skill, compassion, and a wonderful sense of enjoyment by Dr Gabriel Urgoiti and Sue Valentine, these children expressed their life experiences and understanding through words, play and art. As adults, we would find it hard to work through many of the traumas and losses these children have experienced, but they blossomed just because they were helped to tell their own stories, in their own way.

Our project in India and Malawi has already been very successful in improving access to palliative care and pain control for children, and, in the Maharashtra region of India, has

initiated new palliative care services for adults; as well as receiving extensive media coverage.

We were honoured to be present at the Belarussian Children's Palliative Care conference and the exciting establishment of the Eastern European Paediatric Palliative Care Association in Minsk, Belarus. There are a number of excellent and innovative programmes to reach children in these countries but much still needs to be done.

The ICPCN is delighted to announce that Sister Frances Dominica has agreed to become the first Patron of the ICPCN. Sister Frances founded the world's first children's hospice, Helen House in Oxford. An inspiring speaker, she continues to be a strong voice for palliative care for children and we look forward to working together with her, with each one of you, and the children and families we care for, to increase access to palliative care, relief of suffering, and improved quality of life for children in all countries of the world.

May you and those you love be blessed at Christmas, and may the new year be an exciting challenge with many opportunities for our combined voices to be heard.

Joan



DID YOU REMEMBER - 1 DECEMBER WAS WORLD AIDS DAY?

The first day in December was World AIDS Day, with the theme 'Getting to zero: zero discrimination; zero new HIV infections and zero AIDS related deaths. World AIDS Day reminds people that HIV is still a threat to millions, and that there are many things still to be done in the fight to eradicate it.

UNAIDS estimates that there are around 34 million people living with HIV worldwide. It is estimated that 2.5 million of those are children, with many

more millions who are affected by the disease.

During 2010 some 2.7 million people became newly infected with the virus, including an estimated 390,000 children. Despite a significant decline in the estimated number of AIDS-related deaths over the last five years, there were still an estimated 1.8 million AIDS-related deaths in 2010.

The vast majority of people with HIV and AIDS live in low- and middle-

income countries. But HIV today is a threat to men, women and children on all continents around the world.

How much do you know about AIDS? The above information was taken from the AVERT website. www.avert.org

Download the full UNAIDS report from their website at: <http://www.unaids.org>



Sister Frances Dominica agrees to become ICPCN's first patron



The ICPCN is both honoured and delighted to announce that Sister Frances Dominica has agreed to become the organisation's very first Patron.

Sister Frances is the Founder and a Trustee of Helen House, the world's first children's hospice, which opened in 1982 in Oxford, and of Douglas House a 'respite' for young people aged 16-40 which opened in 2004.

In 2006 Sister Frances received an OBE for services to health care. She remains an outspoken advocate for children's palliative care.

Historical Spring Conference 2012

Kristianstad, Norway

12 - 13 April

The very first Paediatric Palliative Care Conference to be held in Norway



kontakt@palliativbarn.np

www.palliativbarn.no/konferanse/index.htm

INTERNATIONAL EVENTS CALENDAR: FEBRUARY - APRIL 2012

More information and contact details for all these conferences, courses and events can be found on our website. Go to www.icpcn.org.uk

February

15	Self Awareness Workshop	Derian House Children's Hospice, Chorley, United Kingdom
23 - 25	Palliative Medicine & Supportive Oncology 2012 - The 15th International Symposium	Key Largo Marriot Bay, Key Largo, Florida, USA

March

14 - 17	IV Latin American Congress for Palliative Care	ExpoUnimed Curitiba, Brazil
18 - 19	Paediatric Palliative Care Masterclass	San Pablo, Brazil
21 - 23	SIOF Congress 2012 Celebrating African Excellence	Upper East Side Hotel, Cape Town, South Africa

April

12 - 13	Historical Conference - The first on Paediatric Palliative Care	Kristiansand, Norway
21 - 1/5	Pediatric Academic Societies Annual Meeting (PAS 2012)	Hynes Convention Center, Boston, USA



ICPCN Paediatric Palliative Care Multi-Professional Masterclass

Improving children's quality of life through Paediatric Palliative Care

19 - 20 March
San Pablo, Brazil

Topics to be covered include:

- ▶ Types Of Interventions: Oncological and Non-Oncological Diseases
- ▶ Paediatric Palliative Care In Newborns
- ▶ Paediatric Palliative Care In Cancer
- ▶ Paediatric Palliative Care In HIV/AIDS
- ▶ Paediatric Palliative Care In Neurological Diseases
- ▶ How to Communicate Bad News
- ▶ Symptom Control
- ▶ Pain: Definitions; Total Pain
- ▶ Who Analgesic Ladder
- ▶ Non- Pharmacological Methods
- ▶ Complementary and Alternative Treatment
- ▶ Drugs And Routes of Administration
- ▶ Opioids Initial Dose, Rescue, Presentation
- ▶ Concept of Agonist - Antagonist.
- ▶ Advantages And Disadvantages of Different Routes Of Administration
- ▶ Psychosocial Aspects: Family And Siblings
- ▶ Spirituality
- ▶ Ethical Considerations in Paediatric Palliative Care

2nd International Multi-Professional Paediatric Palliative Care Course



Nearly 80 professionals from Europe and other continents participated in the first course. Its objective is to achieve significant improvements in PPC structures throughout Europe and other countries. With the first course, we made some important preliminary steps. To continue on this successful path, we aim to hold the course every two years.

The course is held under the Auspices of the European Association for Palliative Care (EAPC) and The Association for Children's Palliative Care (ACT).

For any questions and further information please feel free to contact us any time. We are looking forward to an informative and inspiring course and meeting you again!

Contact:
Bettina Hübner-Möhler
Vodafone Foundation Institute and Chair for Children's Pain Therapy and Paediatric Palliative Care
Email: b.huebner@kinderklinik-datteln.de

ACT & Children's Hospices UK merge to form Together for Short Lives



ACT & Children's Hospices UK merged last month to become a single

encapsulates what the new charity is all about - working to support children and families to make the most of life, recognising that this can only be done by working together - with children, young people and their families, and all our members and partners, with policy makers, governments, funders, supporters and the general public.

Their new web landing page www.togetherforshortlives.org.uk sign posts relevant information on the established ACT and Children's Hospices UK websites, pending the development of a single web platform in due course.

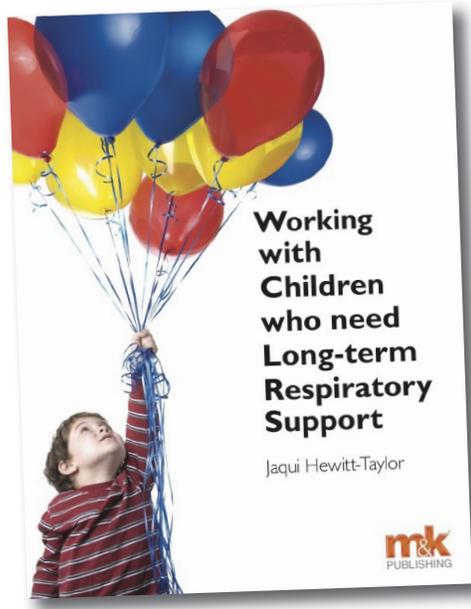
organisation to be known as **Together for Short Lives**.

Barbara Gelb, Chief Executive and Lizzie Chambers, Deputy Chief Executive feel that the name **Together for Short Lives**

To reflect the new brand, all email addresses are now: forename.surname@togetherforshortlives.org.uk.

Contact details
 4th Floor, Bridge House, 48-52 Baldwin Street, Bristol BS1 1QB
Telephone: 0117 989 7820
Helpline: 0845 108 2201
E: info@togetherforshortlives.org.uk

New Publications



This book discusses many of the day-to-day needs of children who require long-term respiratory support. This includes their physical requirements, but also their emotional, social and educational needs, and the needs of their families. The medical and technical aspects of these children's care can seem overwhelming.

However, arguably the more complex and challenging parts of their management concern things that are not directly related to their physical care, such as facilitating their social needs and education. This book aims to discuss all the aspects of care that such children and their families may need, and also to place these in the context of seeing the child as a whole person and as a part of society. To achieve this, six case studies of children who need long-term respiratory support are used throughout the book.

To order your copy of the book from the M & K Website, go to: http://www.mkupdate.co.uk/acatalog/New_Books.html

Together for Short Lives Standards Framework for Children's Palliative Care

Although this document does not contain new material, it is something that practitioners have been asking for for some time. Having a framework of all the pathway standards to refer to in one place will make it easier to monitor practice as you go along, rather than having to dig up hefty documents each time you want to see how your service is performing against the standards.

Download a pdf of the document at www.act.org.uk/standardsframework

The Standards Framework for Children's Palliative Care is designed to work with the four care pathways published by Together for Short Lives (previously the ACT care pathways).

You can find out more about these pathways at www.act.org.uk/care-pathways

Please note the Standards Framework is currently only available in pdf format, and not in hard copy.



“Touching Rainbows” is a surprisingly heart-warming book that gives a voice to children and their families from around the world who have experienced specialised hospice care. Where possible the book has been written in the language of the child, with English translations, and beautifully illustrated with photographs provided by the families and original art works from children or family members.

This book was conceived by ICPCN as a way to highlight the need for children’s hospices and palliative care services.

Around the world the ICPCN estimates that there could be as many as 20 million children who are annually in need of this kind of specialised care. But due to a lack of understanding and awareness for the need, and to limited resources, very few actually receive it.

ICPCN wanted to put together a book that allowed children to tell their own stories about receiving hospice and palliative care. And when this was not possible, due to factors such as their age, the extent of their illness or their deaths, to allow the families or carers to tell their stories from the perspective of the child.

The title “Touching Rainbows” refers to the experiential knowledge that along with the hurt and distress of having a child living with a life threatening or life shortening illness and of losing a child, both the children and their families somehow still manage to find moments of profound joy within the experience. This is evidenced by the words of 12 year old Johan Niewenhuis from South Africa, who said shortly before his death, “I have now fought against cancer for 7 years and I’ve gone through many things. I’m really glad I

got sick, because it made me much closer to the Lord.”

The book tells the story of Sylvia from Indonesia whose greatest wish was to have a wig to replace her beautiful head of hair, of Amy-Claire from Wales whose dream it is to own a

children’s hospice and of young Levi Woolvens from Australia who has MLD (Metachromatic Leukodystrophy) and has taught his family to forget at times that they live with a child with a number of days that are already allocated and to just take ‘every day as it comes.’

These and many other human stories aim to challenge the misconception that hospice and palliative care for children is always a solemn and sombre affair. Sometimes, even in the midst of pain and heartache, it is possible to reach out and to ‘touch rainbows’.

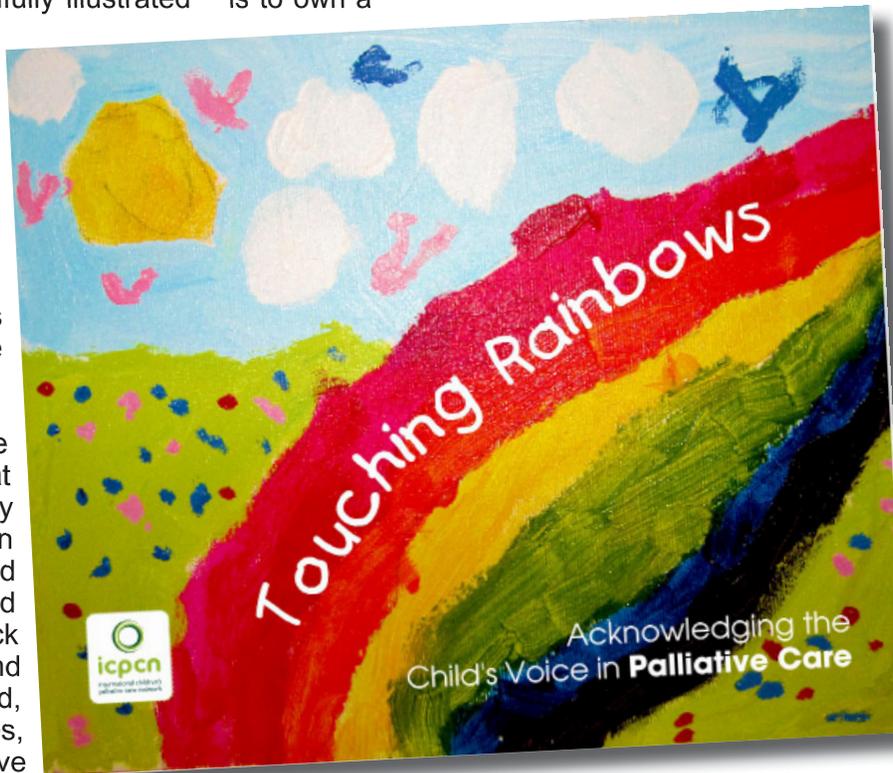
The stories in the book were gathered and edited by Sue Boucher and Professor Julia Downing and published

by the International Children’s Palliative Care Network with funding from Grünenthal, a German pharmaceutical company.

The foreword is written by Sister Frances Dominica, who started Helen House, the first ever children’s hospice, in Oxford, England after her experience of providing respite care to a young girl with a brain tumour and the introduction is written by Joan Marston, Chief Executive of the ICPCN who started Sunflower House Children’s Hospice, one of the first children’s hospices in South Africa.

To order a copy of the book, readers may contact:

Sue Boucher at sue@icpcn.co.za
Barbara Steel at admin@icpcn.co.za
or go to the ICPCN website at www.icpcn.org.uk



pair of Jimmy Choos, pass her GCSEs and to swim in the sea in all her clothes and who says that she has learned that ‘the dates on your gravestone do not matter as much as the dash in-between.’

There’s Nicole from England who speaks with courageous honesty about having a sister in hospice care, Michael from Zambia who is grateful for the pain relief provided to him by the hospice and Rethabile from South Africa whose doctor put his own fear ‘in his back pocket’ in order to allow her to realise her dream to see a real snake. You will read about baby Martha from China who was abandoned by her family and lovingly cared for by the only children’s hospice in this country until she died, how the deaths of sisters Laura and Lynn in Ireland led to the opening of LauraLynn House, Ireland’s first

OUR STORY

We are the Woolvens, Chris, Sam, Jack and Levi ...and this is our story

Levi Woolvens
Written by Sam Birchall



I still remember the day we were given a diagnosis for our 2 year old son, Levi, like it was today. "Your son has an incurable, neurological disorder which he has inherited from his parents called Metachromatic Leukodystrophy (MLD). This has never been seen in either family and it is relatively rare - about one in 40,000. Now we have to make life as comfortable as possible for him. This took some time to process, but bless our neuro doctor, he said he will have a nurse call us who will know about our situation and will have a chat, as she has dealt with a case or two like ours before. Oh dear, someone to talk to about our tragic news.

What the doctor didn't tell us was that the nurse was a specialised palliative care nurse with a whole team of people and resources behind her that she utilised very well. Welcome the Palliative care team of Princess Margaret Hospital! Stephanie, the palliative care nurse, Shelley the social worker and all the wonderful people with expertise in their areas at the hospital. After a year of searching for help and trying to find out what was wrong with Levi, it was like winning lotto! The team offered a haven we had never found before, someone to talk to when Levi was doing something different, helping to get aids to make life more comfortable, getting paper work together to get other services to help manage Levi's condition, even help to obtain financial support. And the best bit is making friends in a world we have never needed to know about before. Although they are there primarily for Levi, we as a family are never forgotten, asking how the rest of the family are, offering opportunities for the families to attend shows, a picnic in the park or even just an ear to listen.

So we no longer struggle to care for Levi due to a tremendous network of help which all started from



"Enter the palliative care team of Princess Margaret Hospital.... After a year of searching for help and trying to find out what was wrong with Levi, it was like winning lotto!

The team offered a haven we had never found before, someone to talk to when Levi was doing something different, helping to get aids to make life more comfortable, getting paper work together to get other services to help manage Levi's condition, even help to obtain financial support."

"We have learnt to take each day as it comes, and a majority of the time we forget the serious nature of living with a seriously ill child who already has a number of days allocated to be with us. But that is life, and this is ours."



our palliative care team. It has been just over a year and there have been many developments in Levi's condition. The loss of his ability to eat or drink orally, loss of eye sight, a very muscle tone-free body which is supported by those who help him with all his needs, and a respiratory system which is constantly being compromised by a cold or flu. All of these moments were anticipated by the Palliative care team and there was always support and avenues to deal with these hiccups.

We have learnt to take each day as it comes, and a majority of the time we forget the serious nature of living with a seriously ill child who already has a number of days allocated to be with us. But that is life and this is ours. As we have regular contact with the hospital, Levi still shares one of his million dollar smiles with the voices he recognizes. Especially when they remember his love of motorcycles and give a great impression of one.

Bbbbrrrrrrrrooooo mmmm!

PERTH, AUSTRALIA

Contact Details

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Tel +61 8 9340 8222
Web www.pmh.health.wa.gov.au



Cancer Life Celebration for children in Sierra Leone



The Cancer Life Celebration took place at the Mwakawago Youth Resource Centre, Kissy, on Wednesday 26 October, 2011. Before the celebration children from various institutions and

representatives from different institutions and people in the host community converged in front of the hall to witness the cultural display by students of the Emiman Primary School.

Once inside the hall, Mr. Joseph Bundor Tarawally, Director of the Crusaders Club Ministry, Sierra Leone, welcomed everybody and explained that the event was organised to mark the birthday of Max, the Founder of the Max Foundation, who passed away at the age of seventeen years as a result of cancer. It was also organised in honour of those who are no longer with us as a result of cancer. After the welcome address, the Chairman of the ceremony was introduced by Mr. Musa Gendemeh. Dr. Owizz Koroma who was Chairman of the ceremony is the only Pathologist in Sierra Leone, at the same time he is head of the Pathology Department College of Medicine and also Director of the Cancer Registry. In his opening remarks he spoke about the World Cancer Declaration as a tool to help bring the growing cancer crisis to the attention of government, leaders and health policy makers in order to reduce the global cancer crisis. He strongly advised that if no action is taken worldwide on the present cancer burden, millions of new cases will emerge and more deaths on cancer will occur. He also spoke on childhood cancer and the cancer life celebration for children.

A short play was acted by students from the Emiman Primary School, Kissy. The play depicted cancer, its causes, warning signs, prevention and survivors. The play was interesting and educating.

Mr. Manfred Musa of the community initiative programme also spoke about the objective of the celebration and its goal. He said that, the goal of the event is to implement a global initiative enabling people living with cancer and their families to celebrate life, give back to their communities and support the most vulnerable of cancer survivors - the children.

Dr. Nylander of the World Health Organization spoke about the disastrous effect of cancer and how it is the leading cause of death around the world. He also spoke on how cancer attacks the body cells and spreads to other parts of the body. He went on to say that cancer can affect any part of the body and also people of all tribes, nationality, rich or poor. However, he emphasised that cancer is treatable. He ended his speech by informing the gathering that WHO is the leading advocate in the fight against cancer.

Joseph Bundor Tarawally
Director: Crusaders Club Ministry
Sierra Leone

20 Travelling Scholarships available from IAHPIC for the ALCP Congress in Brazil

The International Association for Hospice and Palliative Care (IAHPC) is pleased to announce 20 scholarships from the IAHPC Traveling Scholarship Programme, to help support the travel of palliative care workers in developing countries to the VI Congress of the Latin American Association for Palliative Care (Asociacion Latinoamericana de Cuidados Paliativos - ALCP). The ALCP Congress will take place in Curitiba, Brazil, March 14-17, 2012.

Applicants must be living in a developing country, be active members of IAHPC, and actively working in palliative care. Applications from physicians, nurses, psychologists and other disciplines are welcome. If you wish to apply and are not an IAHPC member, you may join by clicking <http://www.hospicecare.com/join.htm>

Preference will be given to individuals who have not received an IAHPC grant in the past three years who have an accepted poster or oral presentation in the Congress or who live and work in a developing country in either the Latin American or the Caribbean region.

Applications are available through the IAHPC website in <http://www.hospicecare.com/Travellscholars/>

Wolfson international bursaries 2011

The Wolfson international bursary grant programme is to increase and improve the provision of palliative care in commonwealth resource-poor countries.

Eligible individuals can apply for a bursary of up to £1,500 to attend one of the listed courses.

There are no deadlines but applications must be received before the start of the course or the next academic year if the course lasts longer than twelve months.

As the budget is limited, once the funds have been allocated the programme will close. From initial application to funding decision could take up to six weeks.

For further information about eligibility and how to apply for this funding, please visit: <http://www.helpthehospices.org.uk/our-services/grants/internationalgrants/wolfson-international-bursaries/>

FOCUS ON CARDIFF 11-13 July 2012



The ICPCN is once again partnering with Cardiff University for the 6th International Cardiff Conference on Paediatric Palliative Care

Abstract deadline: 1 February 2012



The ICPCN is pleased to be partnering once again with Cardiff University and Dr Richard Hain for the 6th International Cardiff Conference on Paediatric Palliative Care.

on Paediatric Palliative Care.

Abstract Submission

Abstract submissions are invited for oral, poster or workshop presentations. Download the abstract submission form from the ICPCN website or ask for it to be emailed to you.

Please email your request to PPC2012@cardiff.ac.uk

The Organising Committee will make the final decision regarding the form of the presentation. Please email your submissions to PPC2012@cardiff.ac.uk

The deadline for abstracts is 1 February 2012. Authors will be notified of acceptance or non-acceptance by email as soon as possible after this date.

Note: Abstracts may appear in black and white in the book of abstracts. Enquiries regarding abstract content to Richard Hain via: taylorhe@cardiff.ac.uk

Conference Venue

The conference will be held at Cardiff University, Main Building. The conference will commence on Wednesday 11th July and end Friday 13th July 2012. The venue is a short walk from the city centre and hotels. There is a train station opposite the building and a frequent bus service from the city centre which stops outside the building.

For more information

You are welcome to contact the conference management team on:

Phone: +44 (0) 29 2087 5508

Email: PPC2012@cardiff.ac.uk

Website: www.icpcn.org.uk



love, joy & peace

To a joyful present and a well remembered past - best wishes for the festive season and a magnificent New Year.

With warmest wishes from the Directors and staff of ICPCN



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Should you wish to contribute to or advertise in ICPCN Network News please contact the Editor, Sue Boucher
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www.truecolourstrust.org.uk